Section 5 - Coalition Building and Community Education/Organizing

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Summary

A key strategy of Allies Against Asthma (AAA) was to increase community connections--both among organizations that have the potential to impact asthma care and among families of children with asthma. This section describes those efforts, including coalition building (supporting the King County Asthma Forum) and community education/organizing (Neighborhood Asthma Committees).

Coalition Building

AAA coalition-building efforts focused on strengthening the King County Asthma Forum (KCAF) by providing it with 1.8 FTE of staff support. KCAF was established in 1998 by Public Health - Seattle and King County and the American Lung Association of Washington State. The KCAF's mission is to establish an ongoing asthma network to communicate about, collaborate on, and coordinate projects that improve and support asthma prevention, diagnosis and management in King County. There are a number of ways in which the collaboration brought about by KCAF has led to strengthening community connections for promoting improved asthma care and outcomes:

- Networking. KCAF meetings and communication provides a way for community-based organizations, medical providers and others to connect with each other to bring about improvements in asthma care and outcomes. Examples of the benefits of networking include: increased knowledge about best practices and organizational resources, and jointly submitted grants.
- Coordination. KCAF increases the ability of providers, community-based organizations and asthma-related projects to work together to coordinate their activities. The Cross-Project Coordination committee (see below under committees) has played a key role in promoting a more seamless system of triage and referral to projects serving different populations and providing different types of service.
- **Integration.** Coordination across care providers can lead to more complete integration of programs and services.
- **Service Delivery.** Grants providing direct services have come about as a result of KCAF resources for development and grant writing.
- **Policy.** The KCAF provides a vehicle for organizations to combine forces and advocate more effectively for policy change.

• **Systems change.** KCAF works with a variety of providers and organizations to promote improvements in the system of asthma care.

Key accomplishments in the coalition building efforts include:

- Strengthening the KCAF governance structure, formalizing the communication processes, and developing new committees. KCAF has a well-developed governance structure defined by periodically updated by-laws (link to bylaws). The KCAF modified its by-laws to relegate decision-making to the Steering Committee, and kept quarterly forums focused on information sharing, education and networking. The KCAF also updated its goals, and set priorities using specific criteria, to guide the work of KCAF from 2005-2008. These priorities shift functions towards more policy advocacy and technical assistance work, and less provision of direct services. As the KCAF has evolved, its committees have also adapted to better fit the direction it is taking. In addition, ad-hoc committees were developed as short-term needs were identified.
- Increasing the number of members and services affiliated with the KCAF. KCAF now has 30 members and 178 people in its information network, representing health care providers, caregivers of children with asthma, researchers, school nurses, pharmacists, academicians, and representatives of non-profit organizations, clinics and hospitals. Asthma projects within King County have been recognizing the value of a KCAF affiliation and so have actively sought these out. In order to better define a project's affiliation to KCAF, three levels were developed and include "core", "sponsored", and "endorsed".
- **Developing and adopting a KCAF sustainability plan,** including identifying top priorities at annual planning retreats, creating a KCAF logo, letterhead, and a public relations packet. A standing Public Relations/Sustainability committee was formed and will carry out the plan. With assistance from the Washington State Department of Health, KCAF worked with a public relations consultant to more effectively convey key messages in the community. In addition to these efforts, proposals submitted as a result of KCAF collaborations will help continue asthma-related work (see Appendix A).
- Increasing both local and national recognition of KCAF as a leader in asthma coalition development. KCAF members have been keynote speakers at meetings held by the Centers for Disease Control and Prevention, the National Heart Lung and Blood Institute, and the New York City Asthma Partnership. Members have also taken a leadership role in The Washington Asthma Initiative and mentored other asthma coalitions in the state.
- **Developing a strong, functional coalition.** In self-administered surveys and interviews, KCAF members reported high levels of satisfaction with virtually all aspects of KCAF, including leadership, decision-making, coalition operations, benefits to themselves and their organization and overall satisfaction. In interviews, members identified areas in which KCAF was providing tangible benefits to the communities, clients and families that they serve.

Community Education/Organizing

The most significant community education/organizing activity was the formation of four Neighborhood Asthma Committees (NACs) to bring parents and other community members into the work of KCAF and to launch local asthma projects. In addition to supporting the NACs, an AAA Community Organizer/Health Educator met regularly with community-based organizations

(CBOs) to promote awareness of asthma and identify ways that AAA could be supportive of their ongoing efforts. The KCAF quarterly meetings also served a community education function, since each forum included a presentation, and community members were invited, including NAC members as well as physicians. Types of attendees varied depending on the presentation topic.

Key accomplishments of the community/education organizing efforts included:

- Establishing four Neighborhood Asthma Committees that bring residents together to talk about their concerns and to take on asthma projects specific to the needs and interests of each particular community.
- Initiating NAC local projects. Rainer Valley/New Holly worked with three local summer camps to help them launch a counselor training on asthma. They also held a World Asthma Day event at Aki Kurose and 90 students participated in a "What is Asthma?" poster contest. The South Park NAC also had a World Asthma Day event. They had a poster competition and they displayed them at Concord Elementary. The Burien NAC hosted an "Asthma Wheel of Fortune Night" at Hazel Valley Elementary with about 80 participants. The Burien NAC is pursuing summer camp counselor trainings and is contacting the Southwest Boys and Girls Club to make arrangements. For World Asthma Day in 2004, the NACs organized teams to participate in the ALA's Asthma Walk, worked with local restaurants to go smoke free for the day, and held a neighborhood health fair.
- Strengthening leadership skills among community members. In 2002 NAC leaders participated in a Tools for Schools training in Washington, D.C., and in 2003 one NAC member presented information about the NACs at a national conference (American Public Health Association) in San Francisco. In June 2004, the local leaders took on a higher level of responsibility for coordinating their individual NACs.
- **Developing and staging an asthma play** to raise awareness of asthma among middle school kids. The play was identified as an important activity by one of the NACs. It was developed with input from the NACs and kids with asthma, and performed three times with a total of 500 attendees.
- Creating a speaker's bureau that draws from coalition membership. Topics offered are diverse and through the discussions, NAC members have become more educated on asthma issues. They are also learning self-advocacy skills. NAC members stated that these speakers are effective and succeeded in changing community member attitudes and knowledge levels.
- Holding quarterly forums to educate the community about asthma. Types of attendees varied depending on the presentation topic. The forums were an important strategy for drawing people in who did not want to get involved in operations of KCAF.

Description of Coalition Building and Community Education/Organizing Activities

An important strategy of Allies Against Asthma (AAA) was to increase community connections, both among organizations that have the potential to impact asthma care and among families of children with asthma. This section describes the coalition-building and community education/organizing efforts and attempts to assess the impact of those efforts on both process and outcome indicators.

Coalition Building

AAA coalition-building efforts were focused on strengthening the King County Asthma Forum (KCAF) by providing 0.3 FTE for coalition coordination, 1.0 FTE for outreach, and 0.5 FTE for administrative support. KCAF was brought together in 1998 by Public Health - Seattle and King County and the American Lung Association of Washington State. Its mission is to establish an ongoing asthma network to communicate about, collaborate on, and coordinate projects that improve and support asthma prevention, diagnosis and management in King County. The KCAF's overall goals are to:

- Improve control of indoor and outdoor environmental triggers of asthma.
- Improve clinical management of asthma by providers, patients, schools and child care organizations.
- Increase community awareness of asthma, including prevention, diagnosis, and management.
- Advocate for policies that improve asthma care

Currently, the KCAF has over 70 individual and organizational members. These members include, but are not limited to health care providers, caregivers of children with asthma, researchers, school nurses, pharmacists, academicians, and representatives of non-profit organizations, clinics and hospitals. For a complete list of members, see the KCAF's website at http://www.metrokc.gov/health/asthma/forum.htm.

KCAF Committees. The Steering Committee provides strategic oversight, direction and vision for the coalition. KCAF leaders (i.e. chair, vice-chair) are elected by the Steering Committee. The standing committees serve as hubs of networking and creative strategizing for solutions to reduce the impact of asthma. They are the driving force behind the KCAF's projects and activities. During AAA funding, standing committees included the following, many of which continue to meet unless otherwise noted:

• Schools Committee. The KCAF Schools Committee provides the oversight, direction and coordination for the KCAF's school-based activities. Key accomplishments of the committee include the development of Asthma Management in Educational Settings (AMES) manual, developing asthma training curricula for teachers, health educators and family support workers, and developing a system for responding to asthma-related school concerns.

- <u>Neighborhood Asthma Committees (NACs)</u>. The KCAF/AAA helped organize four NACs in target community neighborhoods. (See below in the Community Education/Organizing section for more details on the NACs).
- <u>Cross Project Coordination Committee.</u> The Cross Project Coordination (CPC) committee was formed and met bi-monthly to systematically coordinate communication, recruitment, and referrals, and to triage asthma services. Members included representatives from all core and sponsored KCAF projects and any other organizations that wished to coordinate their services with others. The CPC provided a venue for potentially competing organizations to collaborate on the delivery of their services and to coordinate the consistency of asthma messages.
- Public Relations and Sustainability (PR) Committee. The PR committee is responsible for policy work, integration and awareness raising activities. It also allows for timely and effective responses to media opportunities. The activity is coordinated by the Project Manager with support from the public relations consultant. The committee is also providing support (e.g. input, testimonials) for the Attack Asthma Bill that is being presented by the Washington Asthma Initiative to the Washington state legislature this year.
- Quarterly Forum. The Quarterly Forum was not a committee, but it is described here because it served an important coalition building and community education roles for the KCAF. Quarterly forum meetings provided a venue for all KCAF members to network, share information, and learn about asthma. Each Quarterly Forum included an educational presentation as well as time for information sharing. Types of attendees varied depending on the presentation topic. The forums were an important strategy for drawing people in who did not want to get involved in operations of KCAF.

KCAF Projects. The KCAF's projects are another vehicle for making positive changes for those with asthma. These projects have all committed to ensuring a high level of coordination and integration among their services. Selected projects, in addition to AAA, are described below.

Core and Sponsored Projects

These projects have direct oversight and supervision by KCAF and membership on the Cross Project Coordination Committee to insure coordination across projects.

- ACT (Asthma Care Training)— ACT is a clinic-based educational program of the Washington Chapter of the Asthma & Allergy Foundation (AAFA-WA) that is funded by the Centers for Disease Control and Prevention. The program provides a series of three educational sessions for children with asthma, between the ages of 7 and 12, and their families. Children are taught to recognize and describe their symptoms, to understand their asthma and medications and how to use a peak flow meter. Parents receive education about asthma and have an opportunity to ask questions, as well as share their issues and concerns with other parents. Together the family learns how to minimize triggers in their environment.
- <u>Better Homes for Asthma</u>— Funded by HUD and administered by PHSKC, this 3-year research project provides structural housing remediation for conditions that increase exposure to asthma triggers with the intention of lowering exposures and improving health status among children with asthma. Families will also receive one-on-one

- education from trained Community Health Environmental Specialists and tools that will assist them with creating and maintaining an indoor home environment that minimizes asthma triggers and optimizes health.
- Healthy Homes II— HH-II is a research project of Public Health- Seattle & King County funded by the National Institute of Environmental Health Sciences. The goal of HH-II is to compare two approaches to improving asthma control: 1) providing patient education, training in self-management, development of a patient-specific asthma action plan, and case management review by an asthma nurse; and 2) providing the above, plus in-home outreach, education, and resources to address environmental triggers. Findings from the home environmental assessment and the baseline clinical visit are utilized to develop an in-home asthma management plan, tailored to each participant and the conditions in their home.

KCAF Sustainability. As AAA funding ended, KCAF was well on its way to becoming self-sustaining. Several grant opportunities were being pursued and the KCAF Steering Committee had established priorities to pursue from 2005-2008. These priorities reflect a greater emphasis on advocacy for policy change and provision of technical assistance by the KCAF. Specific goals included:

- Advocate for reimbursement of asthma education by health plans, including Medicaid.
- Improve linkages between schools and clinics.
- Advocate for the adoption and enforcement of healthy indoor standards.
- Build political and institutional awareness of asthma by advocating for legislation and getting information out to key policy stakeholders.
- Expand the implementation of the chronic care model by providing technical assistance to develop and implement disease registries, dissemination of guidelines and advocating for reimbursement of asthma education services.
- Reduce exposure to secondhand smoke by increasing the number of smoke-free workplaces.
- Improve communication between emergency departments and primary care clinics.

Community Education/Organizing

The most significant community education activity was the formation of four Neighborhood Asthma Committees (NACs) to bring parents and other community members into the work of KCAF and to launch local asthma projects. The first NAC was formed in January 2002 in the Rainier Valley and New Holly communities. NACs were then established in White Center, Burien, and South Park. The goals of the NACs are to provide asthma education, increase support for families with asthma, develop leadership among NAC members, and develop small-scale projects chosen by the NAC members. The AAA Outreach Coordinator/Community Health Educator worked with leaders from each NAC helping them prepare an agenda for monthly meetings. Each NAC identified one or two members to attend monthly coalition Steering Committee meetings to increase grassroots participation in KCAF governance and to help them understand how the NACs fit into the overall work of KCAF/AAA. These NAC members were 'bridges' between the Steering and Neighborhood Committees facilitating information flow in both directions.

In addition to supporting the NACs, the AAA Community Organizer/Health Educator met regularly with community-based organizations (CBOs) to promote awareness of asthma and identify ways that AAA could be supportive of their ongoing efforts. Recently, this outreach work expanded to include the three AAA Community Health Workers and often included having an asthma booth at local health fairs or presenting information to community health clinics and schools in the target areas. Awareness efforts served as a recruiting mechanism for the AAA CHW home visit program. In addition, the KCAF/AAA website was recently revised to make the site more useful and user-friendly for community members. The site will serve as a resource for community members and other professionals working in the asthma arena.

In 2004, the Community Organizer/Health Educator left the program, and the local leaders took on a higher level of responsibility for coordinating their individual NACs. Leaders received monthly stipends for their work. The KCAF Schools Committee applied for and received a grant from the King County Steps to Health project on behalf of the American Lung Association to fund the NACs as Neighborhood Health Advocacy Committees. Under this grant, the committees will retain a focus on asthma, but may also work on other issues of chronic disease and social justice.

There is no dedicated funding for outreach after AAA funding ends, although King County STEPS to Health will fund a 0.05 FTE coalition coordinator for a year. Any outreach that occurs in 2005 will be carried out by staff or coalition members for whom this is a secondary priority/responsibility.

Measuring Progress in Coalition Building and Community Education/Organizing

Multiple data sources were used to track progress in the AAA coalition building and community education/organizing efforts, including surveys of KCAF and NAC members, meeting minutes, logs and other documents. The primary process indicators for the coalition building and community education efforts are the number of KCAF, NAC and other community meetings and outreach activities as well as the number of community presentations made by AAA staff and volunteers. Outcome indicators include member satisfaction with coalition functioning, development of sustainability mechanisms, new grants awarded to KCAF projects, and the number of projects developed and carried out by the NACs.

Process Indicators

Table 1 lists process indicators for the coalition building and community education/organizing activities. The KCAF met its primary process objectives of establishing a governance structure and meeting regularly, including meetings of the KCAF overall, Steering Committee and subcommittees. The NAC process indicators included number of meetings, and presentations at NAC meetings. In both 2003 and 2004 the four NACs met over 40 times per year, and had over 30 educational presentations per year made at NAC meetings. In addition to NAC activities, over 50 community educational presentations were made, in a variety of settings, including community-based organizations, schools, clinics, professional organizations, universities, state health foundations, and other health departments. KCAF sponsored or participated in a variety of other outreach and educational activities, including health fairs, posters, asthma plays and radio/TV stories.

Table 1. Process Indicators of Success for Coalition Building and Community Education Activities

Process objective	Status/ Indicators
Coalition Building	
Establish governance structure and bylaws	 KCAF coalition and Steering Committee governance structure established Updated by-laws in 2003
Hold regular KCAF Coalition, Steering Committee and sub- committee meetings	 12 Steering and 4 Coalition meetings/year Average attendance (2003): Steering - 15, Quarterly - 22 Average attendance (2004): Steering - 10, Quarterly - 15 Regular subcommittee meetings held for Schools, PR/Sustainability, Cross-Project Coordination
Community Education	
Create and sustain active Neighborhood Asthma Committees	 4 active NACs; meet monthly Leaders identified, attend and occasionally report at monthly Steering Committee meetings 2003: NACs met 44 times, 116 participants 2004: NACs met 40 times, 53 participants 34 interactive self-management presentations to members in 2003 30 interactive self-management presentations to members in 2004
Make presentations to community-based organizations, clinics and schools.	 Number of presentations through June 2005: 52 to community organizations. Three presentations in 2004 at the KCAF quarterly meeting, and two in the first half of 2005. Sectors reached: CBO's, schools, clinic, professional organizations, universities, state health foundations, other health departments,
Attend and participate in other outreach activities	 (Through June 2005) Number and types of activities: 29 health fairs, 1NFL alumni event, 1 fundraiser, 4 school open houses/family nights Held an asthma play at 3 locations for middle school students – 500 attendees 5 radio stories. 3 newspaper/magazine stories Developed KCAF poster for distribution Distributed 33,487 flyers and over 50 posters to over 20,000 elementary schools and families in 4 districts and numerous community sites and clinics.

Outcome Indicators - Coalition Building

Surveys of KCAF members were the primary source of information about coalition building and KCAF community education outcomes. These included a self-administered closed-ended survey administered annually from 2002-2004 and an open-ended telephone survey administered in 2003 and 2004.

Coalition Self-Assessment Survey (CSAS). CSAS is a self-administered, closed-ended survey created by the Allies Against Asthma (AAA) National Program Office. The criterion for inclusion in the survey sample was attendance at least two KCAF-related meetings in the previous year, including standing committees. NAC members were not included in the CSAS sample, as they were not well informed of the KCAF and so would not be able to comment on coalition functioning. Response rates to the survey were 69% in 2002, 85% in 2003, and 83% in 2004.

Table 2 shows the distribution of the survey sample by the role of the respondent in KCAF (e.g., Chair/Officer, Executive Committee (Steering Committee) member). For the purposes of the table, respondents are assigned to a single category even though they often serve in more than one role (see note for assignment rule). A review of the detailed responses showed an increase in people wearing multiple "hats;" for example, the number serving on both the Steering Committee and another committee increased from one in 2003 to five in 2004 and the overall number with multiple roles increased from five in 2003 to 14 in 2004.

There were some changes over the three years the survey was administered in the composition of the KCAF sample. The number of respondents who are Executive (Steering) Committee members increased from 28% in 2002 to 44% in 2004 and the number of individual KCAF members (with no other role) declined from 31% to 10%.

Variable	2	002	20	003	20	004
	Count	%	Count	%	Count	%
Total respondents	36		34		29	
Executive committee	10	28%	11	32%	13	44%
Coalition Chair or	0	0%	0	0%	1	3%
Officer						
Committee Chair or co-	0	0%	0	0%	1	3%
chair						
Committee member	0	0%	5	15%	4	14%
Member (no other	11	31%	6	18%	3	10%
responsibility)						
Staff	5	14%	11	32%	5	17%
Other	10	28%	1	3%	2	7%

Table 2. CSAS Respondent Profile

NOTE: Respondents were able to check more then one category. Table 2 shows a recoding into mutually exclusive categories using an NPO algorithm. Categories higher in the table take precedence: e.g., if someone checked executive committee and staff they would be listed as executive committee.

Table 3 presents results for a number of key indicators of coalition effectiveness drawn from the CSAS results. Highlights of the findings included:

- Respondents felt that they had a voice in coalition activities; however, representation from key sectors in the coalition and member influence were rated somewhat low (for example, only a third of respondents felt that members had a lot of influence over decisions).
- The KCAF decision-making process was considered fair by over 80% of respondents in each year and similar percentages felt the coalition made good decisions.

- Levels of trust were consistently high and reported conflict was minimal.
- KCAF leadership was rated highly approximately 80% of respondents felt that leadership had a clear vision, kept the project on task and sought the views of other members.
- Members were generally satisfied with coalition functioning, including communication, agreement on mission and the degree to which members took responsibility for completing tasks. Overall satisfaction with operations declined somewhat in 2004 compared to the previous two years (from 80% to 60%).
- The function of KCAF shifted over time from being primarily a vehicle for professional networking in 2002 to include operating programs and carrying out policy advocacy in 2004.
- Primary benefits of membership included developing relationships with other organizations, getting services for clients, and increasing professional skills.
- Benefits of participating at both the organizational and personal level outweighed costs for the substantial majority of participants.
- Most respondents felt that KCAF was bringing benefits to their community and was
 improving asthma outcomes for children. A growing number over time felt that resources
 were being identified to implement the changes sought by the coalition.
- In 2004, the majority of respondents reported a strong sense of loyalty and organizational commitment, although both of these indicators were higher in pervious years.

Table 3. CSAS Results: Measures of KCAF Effectiveness

Variable	2002	2003	2004
Total respondents	36	34	29
Representation/Member Influence			
Adequate representation from key sectors (Q6)	33%	43%	35%
Proportion of members with authority to commit support to the coalition (Q9) ¹	30%	44%	39%
Members have "a lot of influence" (Q10)	35%	29%	31%
I have a voice (Q26a) ²	82%	74%	72%
Decision-making			
"Very comfortable" with decision making process (Q13)	50%	53%	52%
Decision-making process is fair (Q14c) ²	81%	82%	89%
Coalition makes good decisions (Q14e) ²	85%	80%	79%
Trust/Conflict			
Can talk openly and honestly at meetings (Q21c) ²	89%	85%	81%
Members respect each others' views (Q21f) ²	94%	88%	86%
More conflict than expected (Q14a)	7%	7%	8%
Leadership			
Leadership has clear vision (Q17a) ²	85%	82%	79%
Leadership seeks others' views (Q17f) ²	88%	82%	72%
Leadership keeps coalition on task (Q17m) ²	82%	77%	79%
Coalition Functioning			
General agreement on mission (Q22b) ²	80%	82%	82%
Action plan is well-written (Q22e) ²	57%	65%	46%
Members take responsibility for completing work (Q19d) ²	82%	77%	79%

Variable	2002	2003	2004
Communication method is effective (Q32a) ²	94%	73%	69%
I am satisfied with operations (Q26c) ²	79%	78%	62%
Purpose of Coalition			
Major function: Professional networking (Q20a)	74%	59%	61%
Major function: Operate programs (Q20f)	44%	59%	57%
Major function: Local policy advocacy (Q20g)	38%	38%	52%
Major function: State policy advocacy (Q20h)	32%	27%	39%
Benefits/Costs of Membership			
Benefit: Developing relationships with other agencies (Q28a) ³	88%	85%	90%
Benefit: Funding for my organization (Q28d) ³	25%	38%	29%
Benefit: Getting services for clients (Q28e) ³	50%	62%	64%
Benefit: Increase professional skills (Q28g) ³	91%	82%	82%
Benefit: Access to policy makers (Q28i) ³	38%	36%	43%
Benefit: Support for policies (Q28k) ³	38%	58%	46%
Helped me learn about asthma (Q34)	94%	85%	83%
Problem: Activities do not reach my primary	31%	33%	29%
constituency (Q29a) ⁴			
Problem: My skills and time are not well-used (Q29d) ⁴	28%	22%	36%
Problem: Not taking any meaningful action (Q29f) ⁴	3%	9%	29%
Problem: Coalition competes with my organization (Q29j) ⁴	10%	15%	14%
Benefits outweigh costs from organizational perspective (Q30)	73%	67%	67%
Benefits outweigh costs from personal perspective (Q31)	90%	70%	82%
Outcomes/Sustainability			
Coalition brought benefit to my community (Q36)	77%	65%	83%
Coalition is improving asthma outcomes for children (Q37b) ²	68%	80%	69%
Resources are being identified to support the systemic/program changes implemented by the coalition (Q38c) ²	38%	51%	66%
Coalition will exist beyond RWJF funding period (Q38d) ²	53%	51%	66%
Overall Satisfaction			
I feel a strong sense of loyalty (Q26d) ²	61%	69%	59%
My organization is committed (Q27d) ²	76%	82%	59%
Satisfied in general with the coalition (Q39c) ²	90%	89%	72%

^{1 - %} reporting more than half of the members or nearly all of the members.

Key informant interviews. In addition to the CSAS, key informant interviews were conducted (by Battelle) with a diverse group of stakeholders on two occasions (between August and October, 2003 and between October and December, 2004). Respondents included KCAF leaders,

^{2 - %} agree or strongly agree.

^{3 - %} reporting some benefit or great benefit.

^{4 - %} reporting this is a minor problem or major problem.

members, outsiders, and staff. The results presented below were taken from the Time 2 (follow-up) Battelle report and focus mainly on questions related to coalition impact and value added of the coalition.

<u>Individual impact.</u> A number of respondents highlighted the value of the personal benefit they received from their participation in AAA/KCAF:

"I learned a lot more about asthma....Being part of the coalition allowed me to see agencies that I wouldn't know about that serve a large population on a low budget. It inspired me to do better work - questioning what else we can do with the money we have."

"But my appreciation for asthma has been heightened from what I have learned and being involved in AAA. It has been an educational venue as well because you are learning things you would not have learned about asthma. The meetings are educational and informative so I have definitely reaped some benefits from being involved."

"This has been a great experience for me. I get to be part of a network of passionate people. It is inspirational. I have learned more about asthma in different sectors. And I've learned a lot about coalitions."

"I have better connections with the asthma community locally. I have grown professionally."

<u>Organizational impact.</u> Respondents spoke about the value of participation to their organization in terms of increased visibility, access to networks, and access to resources:

"Allies has brought funding to the health department. It has also benefited from being part of a national program."

"The opportunity to get advice and counsel in terms of our ACT grant has been very positive. For me, personally, we are a very small organization..."

"School nurses have been concerned about asthma for a long time and we continue to grapple with it... The work with AAA has benefited that. Certainly the AMES manual, although not a direct outgrowth of AAA, it was happening in tandem, and has been a continued resource for school nurses and the school community."

<u>Benefits of collaboration</u>. A number of respondents reported benefits from collaborations that grew out of their participation in KCAF:

"The cross-project coordination has been immensely useful. I thank our IRB for cross-project coordination. They said we could not just pass names around between different projects so they forced us to sit down and work out some good ways to share activities and referral mechanisms that work and that the IRB approves."

"There was certainly more coordination of the projects going on in our target area than there would have been without the coalition clearly. The fact that there is one phone number that consumers and clinicians can call now is a huge benefit - somebody who now has an overview of all the various things and who's eligible for what. I remember that all these things were confusing before so I didn't access things a lot for my patients."

"I see more dialogue and collaboration among organizations around seeking funding. The childcare area is an example between AAF, AAA, and the health department. I also see more respect for a broad range of ways to address a problem. Before there was more competition. Now people fundamentally recognize that problems can be approach from many different ways. Community Health Plan grant is an example."

"Organizations are sharing education and collaborating on programs and grants. For example, AAF and ALA work together, and I think that's rare across the country."

"Right now Seattle schools is working on a small grant with the ALA to do some work on another asthma based curriculum in schools. The fact of Allies and continued relationships that were born there or were supported there working together as it moved to *Steps*, it is clearly an outgrowth of those opportunities."

<u>Impact of KCAF on asthma interventions</u>. The collective nature of KCAF has facilitated implementation of interventions that would have been challenging for a single organization to take on and has helped make interventions stronger. The coalition has encouraged and supported more activities that are multi-sector, and interventions that are intensive and that require paid staff to implement.

"These accomplishments would not have happened without a coalition being there. The proof is in the organizational relationships and the process rather than on asthma morbidity. It is more appropriate for partners to implement models and do direct services in general. Coalitions are better at supporting them and doing integration."

"We [health department] probably could have done most of the interventions without a coalition but not as gracefully and with less coordination and resource sharing."

"I'm skeptical that any of them [interventions] would have happened without the coalition. There might have been talk, but I doubt they would have organized to do it."

"I don't think the level of education for families and the level of education for providers would be there without Allies."

"I think there is a need for a clearinghouse role. I'm not sure if there are any other roles that a coalition could perform other than that and managing grants."

<u>Increased sense of community needs.</u> Participating in KCAF has provided participants with a better sense of the community needs and the barriers to meeting those needs. It helped members think more creatively about solutions. It has provided the community with: a better understanding of asthma care in settings such as schools, daycare centers, and clinics; ideas about how to coordinate across organizational settings to improve care; and direct service programs of high quality that target perceived needs:

"Couldn't have created awareness in certain communities without the coalition. Would be able to have lively discussions on how to improve asthma in King County and what we can do to create policies that help children and families who are asthmatic."

"It has also affected awareness and knowledge among parents, schools, clinics. We're the eyes and ears of providers from what we observe in the home. The doctors asked for this from us. This came out of the Learning Collaborative which [CHW supervisor] facilitates through Allies."

"Once a quarter we try to have a latest in asthma meeting - like a CE program. Very informal though. People have enjoyed it - we move it around. We get some good speakers.... Striking a balance between what community members and professionals wanted. Our speakers have been good at reaching both groups."

"I think that even though we were more rushed in the planning year, it was a good process and out of it we seemed to really grasp the needs and really targeted those pretty well."

<u>Systems Change.</u> Cross sector connections are a priority for KCAF to attempt to change the practice of those treating pediatric asthma. Respondents reported seeing positive changes among providers in terms of getting them to think more systematically about asthma care and delivering a higher standard of care:

"With the clinics we've seen changes in systems that are leading to changes in care. Providers are more aware of optimal care and national guidelines."

"I do think that there have been positive changes in some clinical practices. I also run into families that got environmental changes, such as mattress covers, vacuum cleaners, or filters. Although it is not always clear to me or to them whether it was Healthy Homes or Allies that was responsible."

"Our primary success is in implementing the CHW model. We're also successful at getting the clinics to think more systematically about asthma care. They are more aware of resources and linking patients to it.... We have been successful at raising prevention control and chronic disease control as a priority for kids. This is not traditionally the focus of public health for children which has traditionally focused on acute care and well child care."

"As far as systems change, we've affected systems within organizations, like the clinics, where change happens slowly and then spreads through the organization. Not sure that anything is happening in terms of systems AMONG organizations. There is more awareness but is not translated to systems change."

<u>Community Impact.</u> Families with asthma in the target community have enrolled in the CHW home visit program. Families are making changes in their homes and some are sharing that knowledge with others in the community. Impacts also include: greater awareness of asthma among parents, clinics and housing projects; greater knowledge of how asthma should be managed; and improved asthma care.

"The CHW program has made a difference to managing asthma. We have 152 baseline families now. We have seen hospitalizations go down. We have had an impact on enrolled families but probably not beyond. I don't think that families have been educating their neighbors or friends. The High Point housing project is using our protocols to work in their housing units. In a community setting, not much is happening that is not dependent directly on our project. We could do more with another year. It takes knowing a system well to know where to intervene and that takes time. We're just getting there and we're running out of time."

"The impact in homes is huge. They show me what they have learned from the CHWs and then they teach others what they learned."

"It has also affected awareness and knowledge among parents, schools, clinics."

"They've also had an effect on health care providers. It has helped them give better asthma care to patients."

Outcome Indicators - Community Education

Community Organizing/NACs. The primary outcomes for the NACs are the community projects they carry out. Project examples include:

- Rainer Valley/New Holly worked with three local summer camps to help them launch counselor training on asthma. They also held a World Asthma Day event at Aki Kurose and 90 students participated in a "What is Asthma?" poster contest.
- The South Park NAC also had a World Asthma Day event. They had a poster competition and they displayed the posters at Concord Elementary.
- The Burien NAC hosted an "Asthma Wheel of Fortune Night" at Hazel Valley Elementary with about 80 participants. They are pursuing having summer camp counselor trainings and are contacting the Southwest Boys and Girls Club to make arrangements.
- For World Asthma Day in 2004, the NACs organized teams to participate in the ALA's Asthma Walk, worked with local restaurants to go smoke free for the day, and held a neighborhood health fair.

KCAF member perspectives on NACs. The Battelle interviews contained a number of positive comments about the impact of the NACs.

"The neighborhood groups are growing up and taking charge."

"The NACs have also been active in promoting visibility. They participated in the Asthma Walk. For World Asthma Day they decided to have a Smoke Out in restaurants in Rainier Valley and White Center. All the restaurants they approached said yes. It worked. They're planning to continue with their work to influence neighborhood restaurant policy."

"The group is very culturally diverse. We have people from all walks of life and from various cultures who bring their own perspectives to the table. So when you see that this universal problem is shared my many cultures, I think that is a strength and that doesn't put a tag or label on any one cultural group. It makes it a universal problem and that is definitely a strength."

"I am very happy with the Neighborhood Asthma Committee. That intervention has been very successful in terms of providing education to people in the community and getting people who are usually sitting behind a desk out into the community and seeing people. I've very happy with that."

"One thing that is great is that the NACs are a nice entry way because they are less formal but yet it gives somebody a start in the whole process. If they have gotten comfortable with the NAC meetings, that's a nice first step."

"NACs - we'll see the benefits of this for a long time. We've trained people and have developed expertise among these community members."

"A lot of the NAC members would go back to their physicians and question some of the things the physician was telling them especially about use and directions of medication. They were more vocal and could have dialog with the physician."

"Yes, they serve a need. For parents and kids, the community group meetings [NACs] are important."

"The NAC leaders noticed that people in our communities are concerned about other health issues such as diabetes, hypertension, and depressions. AAA committees are going to become the Neighborhood Health Justice Committees. In addition to asthma they will also take on diabetes, hypertension, and depression... They were getting interest from people with diabetes in the same household as someone who had asthma already."

Lessons Learned

A number of lessons were learned as KCAF/AAA implemented the coalition building and community education/organizing strategies that may be useful for other communities carrying out similar activities.

Lessons Learned about Coalition Building

- A coalition is required to develop the linkages for carrying out a complex project with multi-level interventions. It can help develop a shared project vision, coordinate activities, and get participation of necessary sectors/stakeholders.
- Coalition development requires staffing and other infrastructure support, such as space, communications resources, and capacity to host meetings. Short-term grants (e.g. 4-5 years) are not the best source of funds for this infrastructure support.
- Use multiple methods for engaging participation and obtaining feedback that go beyond meetings and surveys. Decisions are often made in venues that don't attract a lot of

community participants. Having alternative ways to get community participation and input (e.g. focus groups, community meetings) can add integrity to the decision-making process. An investment in email communication, phone calls, visits, and other communication channels is important.

- Resources should be shared as widely as possible within the coalition especially funding opportunities.
- **Fiscal/administrative agents must be willing to cede decision-making authority** for grants that are based in a community coalition to the coalition membership, even though the agent is accountable to the funding agency.
- **Delegate operational decision-making** to an interested, dedicated committee in order to keep meetings such as the quarterly forums focused on issues of interest and benefit to members. The KCAF changed its by-laws and transferred most of the operational business out of the quarterly forum to the steering committee and is now considering further narrowing the group who recommends operational decisions to the Steering Committee to increase efficiency and allow the Steering Committee to focus on strategy and leadership of the KCAF.
- Identify as early as possible individuals who will have the time and be willing to take on responsibilities to carry out the work of the KCAF. KCAF learned that despite significant energy and resources spent dedicated to growing membership size, and regardless of how many people participated in meetings, a fairly small core group took on most of the initiative and leadership in work of the KCAF. The core group who sustained active participation primarily consisted of individuals for whom asthma was a primary focus in their work.
- Implementing projects before taking on policy advocacy work was worthwhile for the KCAF because it helped the KCAF build recognition and understand policy issues on a practical level. It is possible to engage in policy and project implementation work simultaneously, though during the AAA years the KCAF focused on implementation.
- Competing life demands make it difficult for people to take on leadership roles, even if there are financial or other incentives for participating. For example, most of the NAC leaders were working full time and had families, and two of the leaders had major health problems.

Lessons Learned about Community Education/Organizing

- It takes a long time to develop a functioning Neighborhood Asthma Committee, and continual staff support is needed to oversee such items as location, agenda and food.
- Organizers must be sensitive to time commitments. Professionals often have an ideal of what "community participation" means, but often people in the community don't have the time or interest to assume leadership roles.
- Stipends are only somewhat helpful for getting community members to the table. NAC member participation on the Steering Committee increased with the provision of stipends to help reimburse for time away from the job.
- The participatory approach to planning creates satisfaction and allows for the incorporation of multiple perspectives.
- **Having outreach presenters that share information** about a variety of topics effectively engages and informs participants.

Appendix A - Funding Opportunities Pursued

Coalition Building

• Funding opportunities were pursued and awarded (see table below).

Grant/Project	Description/Notes	Start/End Dates	Total Amount
Awarded:			
ННП	HHII is a research project of Public Health-Seattle & King County that is funded by the National Institute of Environmental Health Sciences. HHII's goal is to compare two approaches to improving asthma control: 1) providing patient education, training in self-management, development of a patient-specific asthma action plan, and case management review by an asthma nurse; and 2) providing the above, plus in-home outreach, education, and resources to address environmental triggers.	10/01/01-9/30/06	1,955,839 (includes indirect)
HUD Better Homes for Asthma	This 3-year research project will provide structural housing remediation for conditions that increase exposure to asthma triggers with the intention of lowering exposures and improving health status among children with asthma.	4/15/02 - 4/14/05	998,617 (includes indirect)
ACT	ACT is an educational program of the Allergy and Asthma Foundation of America-Washington State Chapter, and funded by the Centers for Disease Control and Prevention. The program provides a series of 3 educational sessions for children with asthma between 7 and 12 and their caregivers. The program is conducted in English and held at community clinics or community-based organizations.	10/1/03-10/1/04	\$135,000
EPA Home Away from Home	Supporting asthma training for childcare providers and follow-up indoor environmental assessments and education.	10/1/03-10/1/04	\$20,000 (AAFA-WA)
Seattle Housing Authority	Building healthy homes in public housing units for people with asthma. Conducting indoor environmental assessments and trigger reduction education at public housing sites.	10/1/03-9/30/07	\$900,000
Washington DOH	For mentoring other coalitions and developing a public relations plan.	7/1/03-12/31/03	\$10,000
STEPS to a HealthierUS	Healthier STEPS is a CDC grant to provide support to communities to address multiple chronic diseases and related conditions, including: diabetes, asthma, obesity, nutrition, tobacco, and physical activity.	10/1/03-9/30/08	Asthma interventions: o \$112 (CHWs) o \$23,000 (AAFA-

Grant/Project	Description/Notes	Start/End Dates	Total Amount
			WA classes) o \$29,000 (NACs)
Nesholm Foundation	To fund one Community Health Worker.	Awarded	\$30,000 July 05-May 06